

Who is infected with HIV but does not yet know? Detailed data tables and technical notes

Technical Notes:

The U.S. Centers for Disease Control and Prevention (CDC) estimates that about one-quarter of HIV infected persons nationwide do not know they are infected¹ (based on earlier CDC methodology, previous editions of the Epidemiologic Profile estimated that about one-third of HIV-infected persons either did not know they were infected or were not in care in Massachusetts). People unaware of their status do not access HIV-related care and treatment and therefore are unable to experience the benefits of these services, including improved health, better quality of life and longer survival. Additionally, they lack the opportunity to be counseled regarding further prevention of HIV transmission. Applying the national estimate to the number of people living with HIV/AIDS in Massachusetts reported to the HIV/AIDS Surveillance Program (N = 15,966 as of December 31, 2005), and adjusting for completeness of reporting, would yield an estimated 6,261 people who are infected with HIV and do not know it, and 2,818 who know their status but have not been reported. Therefore, the estimated total number of people currently living with HIV/AIDS in Massachusetts, including people known to the system as well as those yet to be identified, is 25,045, or probably in the range of 24,000–26,000 people.

People who are first diagnosed with HIV infection (that they may have been unaware of) at the same time that they are diagnosed with AIDS are considered “concurrently diagnosed”. In the data that follow, a person is considered to have been concurrently diagnosed with HIV infection and AIDS if both the initial diagnosis of HIV infection and an AIDS-defining condition occurred within two months. The profile of people who are concurrently diagnosed with HIV infection and AIDS highlights a population of people who may have first learned about their HIV infection status late in the progression of HIV disease. It is likely that people who are concurrently diagnosed with HIV and AIDS have been infected for more time prior to learning their HIV status than people who learn of their status longer before being diagnosed with AIDS. As such, the profile of people who are concurrently diagnosed with HIV infection and AIDS provides an approximation of people who are infected but do not yet know. This group is one of the target populations for HIV counseling and testing efforts.

When using these data, one must keep in mind the confounding effects of place of birth. People born outside the US may have learned of their HIV status in their native country and subsequently moved to Massachusetts; as opposed to moving to Massachusetts, becoming infected with HIV and then learning about their HIV status late in the course of HIV disease. There is no way to differentiate between these two scenarios from HIV surveillance data, although the latter represents a missed opportunity for Massachusetts

¹ Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. Abstract 11. 9th Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 24-28, 2002

care providers and the former may not. When reviewing the proportion of concurrent diagnoses by race/ethnicity one should note the differences in the distribution of place of birth by race/ethnicity. Fifty-five percent of black individuals concurrently diagnosed with HIV infection and AIDS within the three-year period 2003 to 2005 were non US-born compared to 42% of Hispanic individuals and 10% of white individuals.

Table 1. People diagnosed with HIV infection and AIDS within two months and all people diagnosed with HIV infection by gender, race/ethnicity, and mode of exposure: Massachusetts, 2003–2005¹

	HIV and AIDS diagnosed within 2 months	All HIV infection diagnoses	% diagnosed with HIV and AIDS within 2 months
Gender:	N	N	%
Male	543	1,896	29%
Female	209	786	27%
Race/Ethnicity:	N	N	%
White (non-Hispanic)	275	1,048	26%
Black (non-Hispanic)	278	873	32%
Hispanic	183	680	27%
Asian/Pacific Islander	16	44	36%
Amer. Indian/Alaska Native	0	3	0%
Exposure Mode:	N	N	%
Male-to-male sex (MSM)	209	916	23%
Injection Drug Use (IDU)	104	402	26%
MSM/IDU	10	58	17%
Heterosexual Sex	93	289	32%
Other ²	3	29	10%
Total Undetermined	333	988	34%
• Presumed heterosexual sex ³	214	612	35%
• Undetermined ⁴	119	376	32%
TOTAL⁵	752	2,682	28%

¹ Reflects year of HIV diagnosis among all individuals reported with HIV infection, with or without an AIDS

² Other includes pediatric and blood/blood products

³ Heterosexual sex with partner(s) with unknown risk and HIV status

⁴ Includes those still being followed up for risk information, those who have died with no determined risk, and those lost to follow-up

⁵ Totals include people of unspecified race/ethnicity

Data Source: MDPH HIV/AIDS Surveillance Program, data as of 7/1/06

Note: The category of “presumed heterosexual sex” is used in Massachusetts to re-assign people who are reported with no identified risk, but do report heterosexual sex with a partner of unknown HIV status or risk. Massachusetts uses this category to distinguish these cases from other undetermined cases about which we know less. (It should also be noted that, to be classified in the risk category male-to-male sex (MSM), all that is required is one or more sexual contacts with a man since 1977 regardless of that partner(s) infection or risk status.) Nationally, the Centers for Disease Control and Prevention categorizes “presumed heterosexual sex” cases as “no identified risk” (NIR). As such, comparisons of the presumed heterosexual category cannot be made to national data. Caution should be used in interpreting data for presumed heterosexual, as it is still not clear what the exposure risk is for people in this category. Although a person may not report other risk behaviors such as injection drug use or male-to-male sex to his/her health care provider, it does not necessarily mean that he/she has not engaged in these behaviors. There are many barriers to disclosing HIV risk behaviors in the health care setting such as a limited patient-provider relationship or stigma.

Table 2. People diagnosed with HIV infection and AIDS within two months and all people diagnosed with HIV infection by place of birth and age at HIV/AIDS concurrent diagnosis and HIV diagnosis: Massachusetts, 2003–2005¹

	HIV and AIDS diagnosed within 2 months	All HIV infection diagnoses	% diagnosed with HIV and AIDS within 2 months
Place of birth:	N	N	%
US	416	1,676	25%
Puerto Rico and other US Dependencies ²	67	258	26%
Non-US	269	748	36%
Age at diagnosis:	N	N	%
0-12	-- ³	-- ³	-- ³
13-19	-- ³	-- ³	-- ³
20-24	23	164	14%
25-29	64	276	23%
30-34	108	425	25%
35-39	134	525	26%
40-44	152	500	30%
45-49	116	372	31%
50+	152	363	42%
TOTAL	752	2,682	28%

¹ Reflects year of HIV diagnosis among all individuals reported with HIV infection, with or without an AIDS diagnosis

² Ninety-seven percent of people diagnosed with HIV infection from 2003–2005 who were born in a US dependency were born in Puerto Rico, <1% were born in the US Virgin Islands and 3% were born in an unspecified US dependency

³ Percentages calculated from a numerator of less than 5 are unstable and therefore not presented

Data Source: MDPH HIV/AIDS Surveillance Program, data as of 7/1/06

Table 3. People diagnosed with HIV infection and AIDS within two months and all people diagnosed with HIV infection by gender and race/ethnicity: Massachusetts, 2003–2005¹

	HIV and AIDS diagnosed within 2 months	All HIV infection diagnoses	% diagnosed with HIV and AIDS within 2 months
Males by race/ethnicity:	N	N	%
White (non-Hispanic)	250	914	27%
Black (non-Hispanic)	153	483	32%
Hispanic	127	448	28%
Asian/Pacific Islander	13	33	39%
Total Male²	543	1,896	29%
Females by race/ethnicity:	N	N	%
White (non-Hispanic)	25	134	19%
Black (non-Hispanic)	125	390	32%
Hispanic	56	232	24%
Asian/Pacific Islander	3	11	27%
Total Female²	209	786	27%
¹ Reflects year of HIV diagnosis among all individuals reported with HIV infection, with or without an AIDS			
² Totals include American Indian/Alaska Native and people of unspecified race/ethnicity			
Data Source: MDPH HIV/AIDS Surveillance Program, data as of 7/1/06			